

National Patient and Family Engagement- Learning and Action Network (NPFE-LAN) Caregiver Peer Connection Call

July 12, 2022



Before We Get Started

Please be respectful and remember:

- All lines are muted.
- The lines will be unmuted for questions.
- This call is being recorded and will be made public.
- Do not disclose any personally identifiable information.
- Do not ask for medical advice.
- Each person's situation and experience is unique.
- Before making changes to your health practices, speak with a member of your healthcare team.



Disclaimer

The views and opinions expressed during this call are those of the panelists and do not necessarily reflect the official policy or position of the End Stage Renal Disease (ESRD) National Coordinating Center (NCC) or the Centers for Medicare & Medicaid Services (CMS). Any content provided by the panelists is of their opinions and is not intended to substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.



Moderator



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ESRD NCC

Caregiver/Care Partner – Subject Matter Experts



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Caregiver Resources

For more information on caregiving visit:

esrdncc.org/en/patients/national-patient-and-family-engagement-lan-npfe-lan/

- Tips for Kidney Caregivers
- Transplant Times with a Transplant Care Partner
- Caregiver Peer Connection Call

Tips for Kidney Caregivers

From kidney patients who appreciate their support and the caregivers who understand the experience. Read through the tips and check the boxes you want to accomplish.

Tip 1—Talk About It
The person diagnosed with kidney disease may not act like the person you knew prior to starting treatment. Get to know them as they adjust to treatments. If you have a hard time talking with your loved one, ask to speak with the social worker or another member of the care team.

To keep the lines of communication open:

- Be honest with your feelings and talk about concerns together.
- Do something together, such as taking a walk while you talk.
- Listen openly, stay positive, but don't feel you have to have all the answers.

Tip 2—Be Prepared
Kidney disease comes with many changes and decisions to be made. Learn more about it and the different treatment options.

To learn about kidney disease:

- Visit www.esrdncc.org for resources.
- Create a list of your loved one's medications and medical history. Keep it with you.
- Talk to a healthcare professional about kidney resources.

Tip 3—Set a Schedule
A daily plan keeps things on track and lets you see how your time is spent.¹ It can also highlight if there is a need to ask others for help.

To start your schedule:

- Write down and prioritize your daily and weekly tasks.
- Ask for help when you need it.
- Plan for breaks.

Tip 4—Take Time for You
It's okay, and necessary, to take time for yourself. Make time for activities that help you relax. When you feel recharged, you're better able to help others.

To use a moment for you:

- Take 30 minutes and go to your favorite place.
- Try a relaxation method, such as yoga or meditation.
- Find local and online support groups or talk to a healthcare professional. (Contact your End Stage Renal Disease Network for a listing of local support groups.)

¹ Bova-Collis R, MSW, LCSW. A Caregiver's Wish List: Tips on How Dialysis Patients Can Help Their Caregivers. At Home with AAKP [online]. Nov 2011. Available at: <https://aakp.org/a-caregivers-wish-list-tips-on-how-dialysis-patients-can-help-their-caregivers>. Accessed on June 6, 2019.

TheKidneyHub.org

- TheKidneyHub.org is a safe, mobile-friendly web tool created by the ESRD NCC with help from kidney patients and family members.
- Links to important resources, such as:
 - Goal Setting: Getting Back to me
 - Self-help flash cards
 - Kidney Transplant
 - Home Dialysis
 - Links to on-line communities
 - And more.



Thank You

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